SENILE CATARACTS: AN EXPLORATORY STUDY OF 157 CASES REPORTED IN NEW YORK CITY IN 1955 AND 1956

ELAINE BREGMAN... ET AL.

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SENILE CATARACTS

AN EXPLORATORY STUDY OF 157 CASES REPORTED IN NEW YORK CITY IN 1955 and 1956

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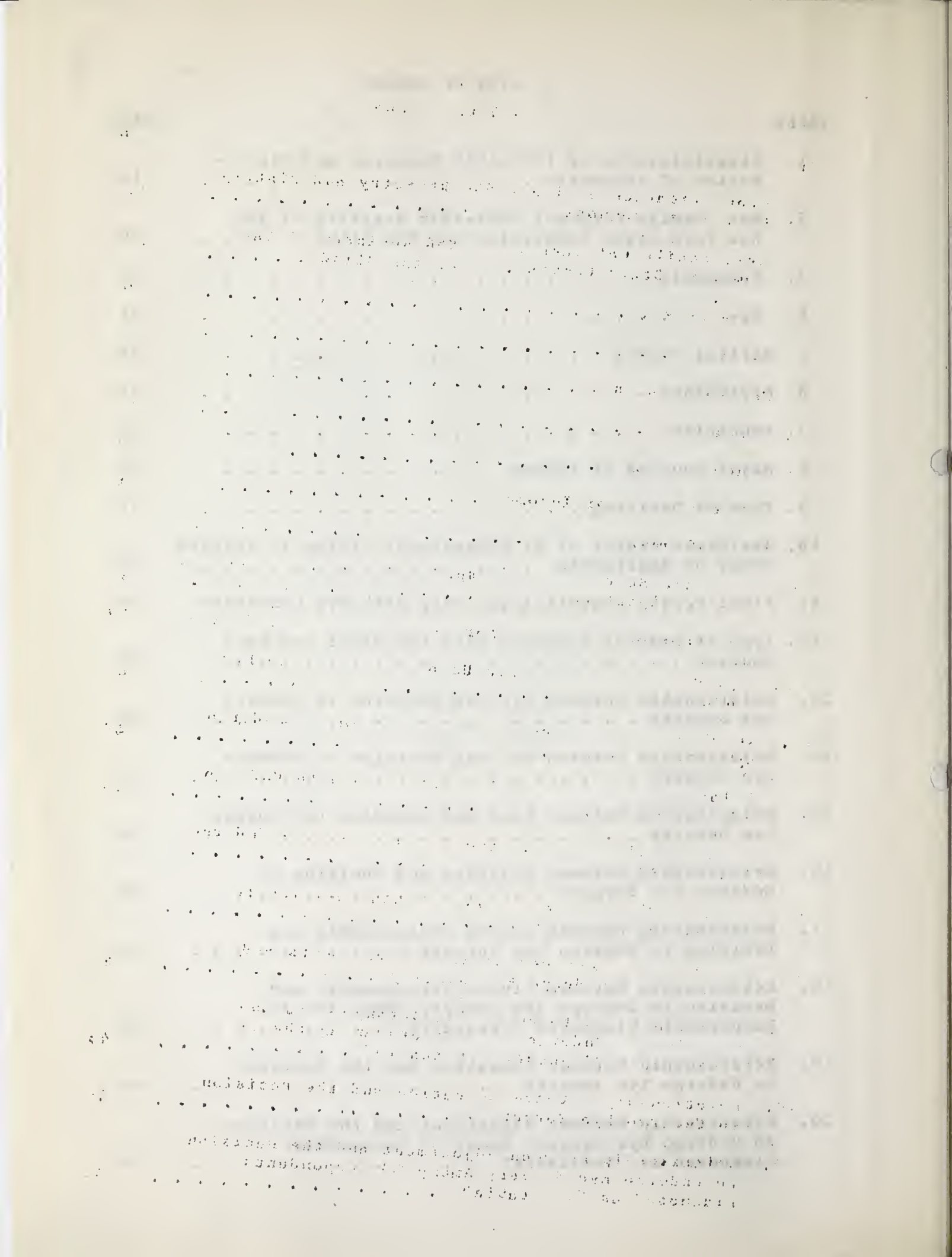

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PREFACE

Blindness has challenged the helping professions for many years, not only because of the physical and social limitations which it imposes on the individual, but also because of its cost to society as a whole. Since one of the leading causes of blindness in this country is cataracts, it is natural that attention should be focused on its treatment.

There are over six hundred organizations in this country interested in some aspect of blindness. The National Society for Prevention of Blindness[1] is interested in all aspects of the problem of eliminating unnecessary blindness throughout the United States. Since its founding in 1908, it has promoted study of the causes of blindness and impaired vision, preventive services, education, and other measures to eliminate these causes and help conserve vision. A voluntary agency specializing in community organization, the NSPB cooperates with the medical profession as well as other professional and lay groups, including public and voluntary organizations on the federal, state and local levels.

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1. Information about the NSPB was obtained from the following:
Carris, Lewis H., "Thirty Years in Saving Sight", Reprint from Sight-Saving Review, Vol. X, No.3, 9/40 NSPB publication #336.

Lancaster, Walter B. and Foote, Franklin M. "The Battle against Blindness", reprint with additions from the Journal of the American Medical Assn. Vol. 145, 1/6/51, pp. 26-29, NSPB publication #161

NSPB, Annual Report, 1955.

NSPB, Forty Years of the NSPB, Thanksgiving Report, 1938.

The NSPB offers advisory and consultation services, and serves as a clearing house for information on all matters relating to care and use of the eyes. It collects, analyzes, and distributes statistical data, reports on medical research, and other studies pertinent to its field of interest. Information is distributed through printed material, press releases, lectures, conferences, radio, TV, and motion pictures. Finally, it is active in promoting legislation.

Among the causes in which the NSPB has participated during its fifty year history are the dramatic victories against "Babies' Sore Eyes" (Ophthalmia Neonaturum), Trachoma, and RLF (Retrolental Fibroplasia). Each of these diseases was at one time among the leading causes of blindness in this country, and each has been virtually wiped out. The NSPB's efforts have also been felt in promotion of sight conservation in industry, the school, and the home. It has campaigned for improved care of the eyes, safety measures to protect the eyes, more legible schoolbooks, improved health and educational services for visually handicapped students. In addition, it has helped organize training programs for teachers, nurses, and social workers who work with the visually handicapped; has contributed to development of medical social service departments in eye clinics and hospitals; and has set up demonstration projects in preparation and placement of trained workers as well as case-finding and follow-up of patients with eye diseases.

The NSPB recognizes that there is still much to be done to reduce the toll of blinding diseases such as glaucoma and cataract which have not yet been conquered. In 1955, the

New York Community Trust made a grant to the NSPB for the purpose of investigating the hidden reasons why people avoid surgery for cataracts. It is from this beginning that the present study developed.

The Commission for the Blind,[2] which has cooperated in this study, is a division of the New York State Department of Social Welfare, and has been in existence since 1913. Its function is to provide preventive, social and rehabilitation services for the blind of the state. Its goals include prevention of unnecessary blindness through education and legislation, and betterment of the condition of the blind through education and training. Since 1945, the Commission has been empowered by law to enforce the mandatory reporting of blindness. Under the law, every social and health agency, private physician and nurse is required to report in writing the name, age, and residence of those legally blind persons with whom they are in contact. The same law established a legal definition of blindness. As a result of this legislation, the Commission is able to collect statistics on the extent and causes of blindness in the state, and the capacity for rehabilitation of each person on its Register.

The Commission is also responsible for maintaining training centers for the blind, promoting sale and use of blind made articles, and encouraging employment of blind workers.

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2. Gillette, David F., Forty Years of Service, publication of the New York State Commission for the Blind, 1953.

Some of the programs in which the Commission, often in co-operation with the NSPB, has taken part include: the program to eradicate "Babies' Sore Eyes"; development of sight-saving classes in public schools; education of the public in detection and treatment of glaucoma; training of pre-school age blind children; special courses for those who work with the visually handicapped; training and placement of blind salesmen at vending stands. The Commission cooperates with public and voluntary agencies interested in blindness and its prevention. Its stake in prevention of cataract blindness is apparent.

At the request of the NSPB and with the cooperation of the New York State Commission for the Blind, the writers, students at the New York School of Social Work under the direction of a member of the faculty, undertook the present study. They and their advisor, Mr. Irving Miller, saw such a project as having important theoretical as well as immediate practical significance.

CHAPTER I

THE PROBLEM

Although the means of prevention of the most common type of cataract, senile cataract, is still unknown, there is an effective cure through surgery. It has been estimated that surgery is successful in restoring useful vision in over 90% of cases for which this treatment is recommended and followed. While there are no reliable figures on the numbers of patients who refuse or postpone recommended surgery, doctors and social workers who are in contact with cataract patients believe there are many such refusals, and that as a result there is much needless blindness from this cause. The consistently high number of cases of blindness from senile cataract offers further evidence to support this belief.

Since, in this country, only communicable diseases of the eye are reported statistically, there are no figures giving the total number of cataract cases in the United States. There is good evidence, however, that cataract is a very common condition of old age. It has been estimated that lens opacities can be found in 65% of persons between fifty-one and sixty years of age, and that this percentage increases with age. Because the progress of many lens opacities (i.e. cataracts) is slow, only a small proportion of these result in serious visual disability before death.[3]

3. Duke-Elder, Sir W.Stewart, Textbook of Ophthalmology, Vol.III, C.V. Mosby Co., St. Louis, 1941, p. 3194. See also Kornzweig, A.L., "Pathology of the Eye in Old Age" Transactions, American Academy of Ophthalmology and Otolaryngology, Vol. 55-56, 1950-51, pp 261-74

Just as there are no figures which give the total number of persons suffering from cataract, there is no nation-wide statistical count of the extent of blindness from cataract. Its relative incidence can be estimated from more limited statistics available. In a study of over twenty thousand recipients of Aid to the Blind,[4] from data collected in the years 1940-41, and drawn from twenty states covering 40% of all the blind in the country, cataract was found to be the single most important cause of blindness. In 19.5% of the cases in this sample, blindness was traced to cataract.

In the same study, over 70% of those reported blind from cataract had the specific type known as senile cataract. Differences in incidence by sex were noted, with 22% of the women and 18.1% of the men in the sample having been reported as blind from cataract. This difference was felt to be partly related to the greater longevity of women. Regarding age distribution, it was found that 80% of the cataract blind in the sample were sixty years of age or older; 60% were seventy or over. Racial differences were also found, with incidence among White recipients being almost 6% greater than among Negroes.[5]

In New York State, we find that of 11,412 persons classified by the State Commission for the Blind as legally blind

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4. Hurlin, Ralph G., Saffian, Sadie, and Rice, Carl E., Causes of Blindness among Recipients of Aid to the Blind, Federal Security Administration, SSA, Bureau of Public Assistance, June 1947.

5. Ibid., pp. 43-45, for all statistics quoted in this paragraph.

during 1950-56, over 23% were registered as blind from cataract. Of these, over 75% were classified as having senile cataract. This data gives further evidence that cataract is a leading cause of blindness, and that senile cataract is its most common form.

In the face of statistics which place cataract as a leading cause of blindness, there is concern over how much of this blindness could have been prevented or could still be reduced through prompt surgical treatment; and what factors interfere with provision for this treatment where it is indicated.

No satisfactory study has been made in this area. Because of its concern with prevention and reduction of blindness, the NSPB saw the need for a study which would throw some light on these questions. The findings could be used in determining the focus of a program to prevent unnecessary blindness from cataract. Such a study could also pinpoint areas in which further study might prove fruitful.

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6. Statistical data provided by the Commission for the Blind of the New York State Department of Social Welfare.

CHAPTER II

BLINDNESS

General Background: The definition of blindness that is used by the federal and state governments is as follows: 'Central visual acuity of 20/200 or less in the better eye, with correcting glasses; or central visual acuity of more than 20/200 if there is a field defect in which the peripheral field has contracted to such an extent that the widest diameter of visual field subtends an angular distance no greater than 20 degrees".[7]

It is estimated that there are 320,000 blind persons in the United States of which about ten percent are under twenty years of age and about 50 percent over sixty-five.[8] The statistical report of the National Society For The Prevention of Blindesss[9] gives the following information with respect to relative incidence of eye diseases:

	Percent
Cataracts	18.8
Disease of Optic Nerve	17.7
Disease of Cornea	14.2
Choroid and Retina	13.6
Glaucoma	11.6

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7. Barnett, Robert M. & Lende, Helga, "The Blind", Social Work Year Book, 1954, N.Y., Amer.Assn. of Soc. Wkrs.,Inc. p.55

8. Roberts, Dean W., Shovor, Jayne, Jacobs, Evelin E., "The Physically Handicapped", Social Work Year Book, 1957, pp 411-412.

9. Lancaster, Walter B. & Foote, Franklin M., "The Battle Against Blindness", J. of the A.M.A., Jan.6,'51, pp.26-29

Glaucoma and cataracts together account for more than 30 percent of all reported blindness. The etiology is unknown.[10]

The rehabilitation program for the blind is based on a system of cooperation between public agencies, federal and state, and private agencies both national and local. In the trend to increase government participation in this area of social welfare, the federal government has enacted a considerable number of legislative measures beneficial to the blind. Services such as home teaching for the adult blind, help to the newly blind to adjust to their handicap, workshops and vocational guidance and adjustment service have been established by both the public and the private agencies.[11]

"The most significant federal legislative action during recent years was the passage of the amendments in 1943 and 1954 to the Vocational Rehabilitation Act of 1920. According to this act the federal government through the office of Vocational Rehabilitation of the Department of Health, Education and Welfare assumes the necessary state administration cost and cost of vocational counseling and placement, while certain other expenses including vocational training are shared by the state and federal governments. An average of 3500-4000 blind persons each year are being rehabilitated into employment as a result of this law."[12] The Randolph-Sheppard Act of 1936, The Business Enterprises Program for the Blind, authorized by the Labor-Federal Security Appropriation Act of 1946, and the Wagner-O'Day Act of 1938 were

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10. Ibid, pp 26-29
11. Social Work Year Book, op. cit., passim.
12. American Foundation for the Blind, "The Blind", July 1955 Publication, American Foundation for the Blind, p. 10.

all for the purposes of vocational rehabilitation and employment opportunity for the blind.[13]

One half of all the blind in the United States are receiving direct financial aid.The federal government provides such aid partly as aid to the blind and partly as old age assistance. Aid to the blind under the Social Security Act must be granted on the basis of individual need.[14]

There are two national agencies of professional workers for the blind, The American Association of Instructors of the Blind and the American Association of Workers for the Blind. The American Foundation for the Blind was established in 1921 by action of these associations. It carries a variety of services and activities for the interests of the blind. The activities include consultation and field service, special services to blind individuals, publications of professional literature, special library on work with the blind, and continuous research.[15] The aims are the prevention of all unnecessary blindness, and the betterment of the condition of the blind.

Psychosocial Factors in Adjustment to Blindness: In considering the factors that constitute the individual's adjustment to blindness, major emphasis is placed upon reactions of the family to a blinded member, the community attitudes and the individual's own feelings about his handicap.

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13. Ibid., passim.
14. Ibid. p.11.
15. Ibid. p. 13

Attitudes and reactions of the family members reflect themselves in the socialization of the blind individual as it does in the psychosocial maturation of a young child. Fearfulness and dependency are apt to grow out of visual handicaps. If the visual defect necessitates depending partly upon others, the individual may become retarded when he should be achieving independence and self-assurance. If emotional blocking exists in parents or others in the family closely related to the individual, the problem becomes deep-seated and even more intensified. Families with a blind member must achieve a balance between such conflicting impulses and attitudes as 'rejection' and 'overprotection' if they are to give optimum help to a blind loved one.

Although families can be educated to adjust and to alter their attitudes toward their members more complex problems lie in the community attitudes toward the blind, which strongly determines their adjustment. It has been said many times and in many ways that the greatest difficulties confronting blind people are the ambivalent, inconsistent and stereotyped attitudes of the sighted, as this limits normal social intercourse between the blind and the sighted.

Blindness in a sighted society inevitably produces social distortions and inequalities. The blind individual has tended allegedly to claim for himself special rights, to feel that others are bound to render him services and that he himself is freed from obligations to others. These are compensations due to him and the more the prejudice with regard to the blind is magnified, the more he is apt to consider that these compensations should be increased.

Community attitudes play a crucial role in one of the most important areas for adjustment to blindness, namely, employment. Recently much has been done in education of the public around the employability of handicapped workers. However, such limiting factors as mobility, agility, and adaptation to changing situations make employers skeptical and reluctant to employ blind workers. Yet, if the blind person wants to live a close to normal life, he must work.

Society views critically the man who does not work and this in turn is reflected in the individual's perception of his own worth and dignity as an individual. There are few areas, perhaps those requiring specialized intellectual and artistic abilities, where the blind person can compete with the sighted in a way approaching equality.

The community confronts the blind person with inconsistent attitudes, he is either a prophet or a pariah, he is dependent and inadequate and bereft of all capacities, or he has special faculties - a sixth sense, etc. He should know his place on one hand or, on the other hand, he lacks initiative and drive. If Helen Keller and Alec Templeton can do it, why can't he? The blind person, in a similiar vein, has inconsistent attitudes toward the sighted.

Opinions differ with respect to the individual's own feelings about his blindness and the extent to which loss or serious impairment of one sense affects the character and the personality.

Ralph V. Merry in The Education of Visually Handicapped Children acknowledges that there are personality difficulties but he does not attribute them all to the loss of sight. He

writes "While blindness may be responsible for certain personality difficulties, it seems more reasonable to suppose that the majority of these maladjustments results from the social situations arising from lack of vision, rather than from the physical handicap itself."[16]

Thomas D. Cutsforth, author of The Blind in School and Society, takes a more definite stand by saying, "It is generally supposed that blindness represents the mere absence or the impairment of a single sense. On the contrary, blindness changes and utterly reorganizes the mental life of the individual. The earlier this frustration occurs, the greater the reorganization that is demanded and the greater, also, the effect of the frustration upon seeing individuals whose attitudes determine the hygiene of the blind."[17]

We should, however, distinguish among those born blind, those who become blind in later life, and those who have partial vision. Blindness is a factor creating conflicts in the individual which may affect his mental health. The sources of conflict are 1) in the restrictions that blindness imposes and 2) in the reactions of society to blindness. The restrictions due to blindness include restriction in the range and variety of concepts. Blind persons build conceptions of the world by relying exclusively upon tactual and auditory perceptions and kinesthetic experiences. Hearing, however, does not convey any concrete ideas of objects as such. Tactual perception also has distinct limitations because of the inherent necessity for direct contact with the object to be

16. G. Farrell, "Mental Hygiene for the Blind". Am.Assoc.of Instructors of the Blind. Michigan School for the Blind, June 27-30 1938, p. 135.
17. Ibid. p. 136

observed. On the other hand, many objects cannot be touched and it is difficult for the blind individual to perceive them.[18]

There is also restriction in the ability to get about which make the blind dependent upon others, thus affecting social relationships and attitudes in varying ways and degrees. Besides being limited in the perceptual field, blind individuals, from infancy on, are exposed to a reduced number and variety of experiences. The restriction in the ability to get about must be recognized as exerting great influence on the over-all development of the blind child.

Later, in life, the blind person, expecting to be helped in all respects, may regress to a level of dependency which is characteristic of infancy. On the other hand, the blind may revolt against being aided in many of the activities which he knows seeing persons can pursue independently. Either of these attitudes, regression or hostility, if it persists as a disturbing influence, indicates a lack of adjustment growing out of the non-acceptance of the handicap.

The loss of sight also imposes restrictions in the control of the environment since sight is the one sense which overcomes distance and gives at the same time details and relationships of form, size, and position. This "object quantity" of visual experiences permits a contact with and control of the environment far greater than that achieved by the other senses. Lack of sight causes, therefore, a detachment from the physical, and to a less degree, from the social world.[19]

18. W. Donahue and D. Dabelstein, ed. Psychological Diagnosis and Counselling of the Adult Blind. New York, Am.Foundation for the Blind, 1950, pp.35-36
19. Ibid. p. 38

For the newly blinded the restrictions imposed by the handicap and the knowledge that he will have to live with them for the rest of his life are experiences of extreme severity. He reacts not only to the attitudes of society toward blindness but also toward those within himself. The shock of blindness may lead to withdrawal, suicidal intentions, rejection of religion, regression and hostility. Reactions to blindness are influenced by the intensity and extent of such feelings prior to blindness. In older persons reactions to blindness may be complicated by additional anxiety and questions about self-worth related to diminished sexual powers or lack of outlet for sexual need. In addition to subconscious reactions, cultural patterns, such as those which make the "blind" synonymous with "beggar" etc. may contribute to false and primitive fears about blindness.[20]

Success in overcoming the obstacles of blindness is mainly a personal and lifelong struggle for the handicapped individual. However, his success or failure will be determined by his and the community's attitudes toward him as a blind person.

All handicapped individuals must make their adjustment to the attitudes of the public. In view of community attitudes to the blind person, adjustment requires a self confidence rooted in feelings of security and a sense of belonging. Early childhood experiences are generally regarded as determining the future attitude pattern of the individual toward society. The earlier in his life the blind individual can

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20. B. Lowenfeld, ed. The Blind Preschool Child. "Psychological Factors in Casework with Blind Older Persons" by H.Lokshin. New York Am. Foundation for the Blind, 1947, p. 79

New Outlook for the Blind, v. 51, No. 1, Jan 1957, pp. 1-8.

develop satisfactory relationships with the members of his family, who are his first contact with the seeing world, the greater is his opportunity to develop a sense of security with which he can meet the problems which will confront him as he grows up.

In our culture, physical variations carry psychological and social significance; that is, they influence behavior far beyond the neuromuscular mechanisms involved. To understand the problems of the blind one needs to ask what changes in an individual's behavior arise by virtue of the fact that he is blind. To answer this, one should consider what is known about the behavior of blind persons, and what are the sources of such behavior, or in terms of what concepts can the known facts be described.[21] Lewin distinguished between the phenotypic behavior, where the person reacts to his blindness with aggression or submission, and the genotypic behavior[22] which is with insecurity and conflict.

Since our culture is one of normally seeing persons, the blind individual is forced into the critical area of overlapping situations. His position is that of an underprivileged minority group member who is required to live in a world in which certain satisfactions open to persons with sight are difficult or impossible for him to achieve. The blind person ha to live in a world dominated by seeing persons, but he is not allowed to be of that world. He lives on the margin between two ways of life, the way of the seeing and the way of the

21. W. Donahue, op. cit., p. 29.
22. Ibid.p . 14

blind, but cannot consistently follow either. There are two ways in which the blind may escape from his marginal position: 1) to withdraw from contact with the seeing and to associate only with the blind and 2) to try to escape into the dominant majority to conceal his handicap. His successful adjustment will depend on changing attitudes of the surrounding environment, clarification of behavior possibilities, preparing for the hostility of the seeing world and providing for psychotherapeutic counselling for parents and their children.[23]

Cataract Blindness: Cataract is a clouding of the lens inside the eye. The normal eye has a transparent lens, through which light may pass easily. It lies within the eyeball, just behind the pupil.[24] The function of the lens is to focus the rays of light upon the retina of the eye so that images can be seen. The retina is a sensitive membrane inside the eye which receives the image and sends it to the brain through the optic nerve. Vision depends on the free passage of light through the lens of the eyes.[25] When a person has cataracts, the lens becomes clouded, or opaque, and light cannot go through to the retina.

Frequently, the first sign of trouble appears as a blurring of vision. Patients with developing cataracts often complain of spots before their eyes. Another frequent symptom in the early stages is myopia (near sightedness). Presence of these symptoms does not always mean that a person has a cataract. As the cataract progresses, the lens cloudiness will increase in size.[26]

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23. Ibid, p. 14
24. John W. Henderson, MD, "Common Misconceptions about Cataract", Outlook For the Blind (American Foundation for the Blind, 1947), p. 226.
25. Conrad Bernes, MD, ed., The Eye And Its Diseases (W.B. Saunders Co., Philadelphia & London, 1949), p. 462.
26. Charles A. Perera, MD, May's Diseases of the Eye (Williams and Wilkins Company, 1953), p. 265.

There are several causes for cataracts. Sometimes cataracts may develop as a result of other diseases of the eye or injury to the eye. Metabolic disturbances or diseases of other parts of the body, such as diabetes, may also lead to cataract. Some forms of cataracts are congenital, that is, present at birth. Certain vitamin deficiencies may also have some bearing on the development of cataract. The majority of cases, however, develop as a part of the aging process.

Cataracts are often classified according to the age at which they appear, i.e. congenital, infantile, adolescent, adult or senile.[27]

Senile cataract, which is the form associated with the aging process, is the most frequent form of cataract. It is quite common after the fiftieth year; occasionally it is seen as early as forty. Almost always both eyes are involved, but generally one in advance of the other. Senile cataracts are progressive, that is, the opacity (cloudiness) becomes more dense as the patient grows older. This may not, however, seriously affect vision until the cataract is in the center of the lens, at which point light will not pass through the lens unobstructed.

There are four stages in the development of senile cataracts: incipient, immature, mature, and hyper-mature. In the mature stage, the cataract can be separated easily from the capsule or outer covering of the lens; it is said to be "ripe". The cataract may continue in the mature stage for a long time. However, once it reaches the hyper-mature stage, the outlook for surgery is less favorable since the procedure is more difficult than it is in the earlier stages.

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27. Daniel B. Kirby, AM, MD, ILD. Surgery of Cataract (J.B. Leppincott Co., Printed in the United States of America, 1949) p. 183.

The extraction of the lens by operation is the only means of relief for senile cataract. Other forms of treatment may be applicable to other types of cataracts. There are no rigid rules that determine when a cataract is operable. It used to be thought that a cataract had to become "ripe" before it could be operated on. Medical authorities now believe that the favorable time for extraction of senile cataract is when the vision of the better-seeing eye has failed enough to interfere with the patient's normal daily activities and comfort.[28] Sight can be restored by removal of the cataract if the only difficulty with the eye is the opacity (cloudiness) of the lens. Where there are other complications of the eye or some serious physical condition present, surgery for cataract may not be recommended. Senile cataracts cannot be cured without an operation. Eye drops or injections have no curative value. From the early stage of cataract on, it is very important that the eyes be examined periodically. It is also important that the patient have a general physical check-up; in this way the conditions which might complicate surgery would be discovered and cleared up if possible.

There are two kinds of surgery for senile cataract: intra-capsular and extra-capsular. In the former kind, the lens is removed in its capsule; with the latter method, the capsule is opened before removal of the lens. At the present time, both eyes are never operated on at the same time. After an operation, for the first few days, bandages may cover one or both eyes even though only one eye has been operated on. In

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28. Perera, op.cit., p. 271

some cases, only the eye which has been operated on is bandaged. Usually a patient stays in the hospital from eight days to two weeks and it will be four to six or more weeks before he can be fitted with special glasses. Furthermore, glasses are not prescribed until all signs of irritation have disappeared.[29] Many patients think that right after surgery, they will be able to see as well as they did before they had cataract. They may be disappointed to learn that it may be several months before they can get accustomed to their new glasses and to the differences in the color and size of objects. It will be some time before their eyes are readjusted.

A favorable result and useful vision should follow cataract extraction in almost all uncomplicated cases. Following surgery, there is generally good vision with glasses. As mentioned already, the success of surgery is dependent not only upon surgical skill, but upon exclusion of those complicated cases which cannot be improved by an operation. In addition, if recommended surgery is not done when it is considered favorable there may be less chance for success at a later time.

Medical science has made it possible for the blind to see in the case of cataract if the patient seeks medical advice early and follows his eye physican's advice.

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29. Ibid., p. 275

CHAPTER III

METHOD AND SCOPE

This study is exploratory-descriptive and utilizes a questionnaire as its major tool. It inquires into the socio-economic, ethnic, cultural and medical background of 157 respondents in an attempt to find out why more people with treatable senile cataracts do not undergo surgery.

The purpose of this study is twofold:

1. To elicit the variables which determine an individual's decision to accept or reject surgery in view of the fact that current surgical techniques afford an excellent chance for restoration of vision.

2. To get data which may serve as a basis for the development of preventive programs.

Individual interviews with a selected sample of senile cataract blind in New York City were carried out during the months of February through April 1957. The interviewees were reported either by clinics, private physicians, or social agencies to the State Commission for the Blind during the years 1955 and 1956. Although New York State law requires the reporting of legally blind persons to the Commission, the degree of coverage is uncertain. Estimates range from 50 percent to 90 percent.

The decision to study cases of senile cataracts stems from the fact that senile cataracts are estimated to comprise at least 75 percent of all cataracts.[30]

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30. N.Y.State Commission for the Blind Statistics, "Causes of Blindness", According to Topography and/or Site and Primary Diagnosis for 11,412 Individuals Classified Blind 1951-1955 Mimeographed Table, Comm - 310, 11-10-56.

The decision to use cases registered in 1955 and 1956 was dictated by the need for accurate information about time sequences between onset of eye difficulty and initial medical contact, between seeking help from more than one source and the acceptance or refusal of treatment, etc. Further, people more recently registered would be more accessible for interviewing and could be expected to produce the highest possible degree of reliable and accurate data.

Conceivably then, the data compiled on blind persons living in other parts of the country or reported to the State Commission during different years, or from those cases not reported to the State Commission might differ from the data reported in this study.

It was hoped that we would be able to interview at least 200 senile cataract blind in the city registered during the year 1955. There were 223 such cases on the State Commission's registry for that year. Names and addresses were taken from this registry and letters were mailed to this group informing them of the current study and requesting cooperation by returning an enclosed postal card indicating the preferred time and date for an interview. Whether or not these postal cards were returned, a contact was attempted. Prior to this a test run of 15 names taken from the 1954 register was used to test the adequacy of the questionnaire. Based on the results of this preliminary interviewing, changes were made in the questionnaire.

Within the first two weeks of interviewing it became evident that many of the expected obstacles and technical problems in interviewing materialized. Many of the people

in our sample had died, moved or could not be reached after repeated attempts. Interviewing was hampered in many cases by language barriers, senility or refusals. In addition there was a discrepancy between the quoted 223 persons in the 1955 senile cataract statistics and the actual number of 187 gleaned from the registry. Movement out of the city, deaths, duplication and temporary unavailability of some of the records accounted for this discrepancy. After a period of two weeks, it was evident that the total number of completed interviews might only be about one hundred. Thus the study was expanded to include the 1956 registry. Because these people were relatively "fresh" many of the problems of inaccessibility presented by the 1955 sample were reduced. In order to meet deadlines, it became necessary to conclude interviewing before the 1956 registry was exhausted. The total completed interviews amounted to 157 - 43 short of the original goal.

In order to insure a high degree of reliability, interviews were conducted in as uniform a manner as possible. The interviewers were instructed to ask questions always in the same manner, sequence and to use the phraseology of the questionnaire. A set of general instructions (See Appendix II) was prepared to facilitate this task and to clarify the questionnaire still further. We also realized that the reliability of the findings depended largely on the accuracy of the answers received. We also expected to encounter difficulties insofar as some of the questions were "emotionally charged" and others required good recall for sequences of events, etc.

Of course we must recognize that some of the answers obtained from our respondents might have been unconsciously or consciously distorted (for the reasons discussed above as well as others) and to that extent our findings are affected. We do, however, believe that the large number of respondents covered, the relatively small number of refusals, the relatively uniform training, experience and motivations of the interviewers and a variety of precautions justifies our confidence in the data.

The questionnaire is based on the overall assumption that the socio-psychological background of the respondent plays an important role in his decision to undergo eye surgery. Thus the questionnaire was divided into four areas of inquiry (See Appendix I)

1. Identifying Information
2. Social Data
3 Medical History
4. Attitudes and Perceptions Related to Visual Difficulties.

With respect to the foregoing, questions were focused to obtain specific information. In regard to the medical information, we attempted to determine such things as the time span between the respondent's awareness of eye difficulty and his initial attempt at getting help or advice; the nature of this help (whether it was medical or non-medical) and the kind and number of additional consultations and resulting recommendations;the reasons for decision to accept or reject surgery on the part of those diagnosed "treatable", "untreatable" or where the prognosis was "uncertain" as well as the outcome of surgery for those who sought this treatment.

It was felt that the type of medical help sought (e.g. private practitioner versus clinic) and the nature of interpretation of the eye difficulty and of the required treatment might influence a respondent's decision to undergo surgery. It was also felt that secondary medical conditions might influence this decision. It was deemed important to know the respondent's previous medical eye history as well as other kinds of help or advice he received and whether he had friends or relatives who had undergone eye surgery.

In the area of identifying characteristics we determined age, address, citizenship status, ethnic background, educational background, religion and marital status. Overall characteristics of the sample can be obtained from this information.

Since human beings do not operate in a vacuum and since one of our hunches has been that familial, ethnic, cultural mores and pressures as well as socio-economic status would influence an individual's decision regarding surgery, it was decided to include questions pertaining to family composition, place of residence (living alone or with family or friends), family attitudes, religion, etc.

The respondent's level of adjustment to his handicap, his personality makeup, overall attitudes to himself, his family, and his environment were felt to be relevant to the understanding of why people do or do not undergo surgery. Further, the respondent's own perceptions and understanding of his eye difficulty as well as his perception of cost of surgery and duration of hospitalization involved would be relevant and of interest in further studies. To measure "attitudes"

and "adjustment" we used or adapted some of the questions utilized in another study.[31]

In summary, it can be said that our questionnaire operates on the assumption that "behavior" of people in general, and also the behavior of the individuals in our sample is influenced by other than rational considerations. The intent is to gain understanding regarding the "How" and "Why" people do or do not avail themselves of proper medical services.

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31. Fitting, Edward A. "Evaluation of Adjustment to Blindness", American Foundation for the Blind, No. 2, Research Series, 1954

CHAPTER IV

FINDINGS

In general our findings give support to the following:

1) that our sample includes a considerable number of people with treatable senile cataracts, many of whom have not undergone recommended surgical treatment.
2) that some people categorized as untreatable were so classified as a consequence of unsuccessful surgery; others undertook surgery subsequent to an unfavorable prognosis.
3) that our sample is composed largely of people who are aged (seventy and over), financially dependent and socially deprived.
4. that the nature and quality of the medical experience (e.g. by whom and how the medical situation was interpreted) has a bearing upon the client's decision concerning treatment.

The tables which follow elaborate the foregoing. Unless otherwise indicated in the table title, the reference in all tables is to 157 people interviewed.

Identifying Data

TABLE 1

CLASSIFICATION OF 1955-1956 REGISTRY AND DISTRIBUTION OF PROGNOSIS

CLASSIFICATION	TREATABLE	UNTREATABLE	DOUBTFUL	NO PROGNOSIS	TOTAL
	No.	No.	No.	No.	No.
Completed Interviews	71	45	31	10	157
Not Contacted	8	7	5	1	21
Not Home	4	7	9	0	20
Wrong Address	35	20	26	11	92
Refusals	5	4	13	4	26
Unable to be Interviewed	11	17	10	1	39
Dead	10	6	8	1	25
TOTAL	144	106	102	28	380

Originally there were 380 names on the registry. Of these 144 (37 percent) were considered treatable, 106 (28 percent) were considered untreatable, 102 (27 percent) had a doubtful prognosis and no prognosis was given for 28 (eight percent). The prognosis is as given by the physician reporting to the State Commission.

We obtained full interviews from 157 (41 percent) of the registry. The 223 (59 percent) not interviewed, were unavailable for various reasons. Twenty-one (six percent) were not contacted, 20 (five percent) were not at home when visited, 92 (24 percent) had wrong addresses and 26 (seven percent) refused to be interviewed, 39 (ten percent) could

not be interviewed because of illnesses either mental or physical, 25 (seven percent) were dead.

Seventy-one (44 percent) of the sample were considered treatable as compared with 37 percent of the total registry who were considered treatable. Forty-five (30 percent) were untreatable in our sample as compared with 28 percent of the registry, 27 percent had a doubtful prognosis in the registry and twenty percent of the sample had doubtful prognosis. Eight percent of the total registry had no prognosis given as did six percent of the sample.

TABLE 2

SEX: SENILE CATARACT 1955-1956 REGISTRY, NEW YORK STATE COMMISSION FOR THE BLIND

	Completed		Not Completed		Total	
	No.	%	No.	%	No.	%
Male	69	44%	96	43%	165	44%
Female	88	56%	127	57%	215	56%
TOTAL	157	100%	223	100%	380	100%

Of the 380 people in the registry, 165 (44 percent) were males and 215 (56 percent) were females. Eighty-eight (41 percent) of the female population were interviewed and 69 (41 percent) of the male population were interviewed. There were then twelve percent more females than males in the registry and exactly the same percentage (twelve percent) more females than males in the sample interviewed. Of those not completed there were fourteen percent more females than males. Thus, the distribution remains proportional throughout.

TABLE 3
PROGNOSIS

CLASSIFICATION	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
Treatable	22	32%	49	55%	71	44%
Untreatable	29	42%	16	18%	45	30%
Doubtful	13	19%	18	21%	31	20%
No Prognosis	5	7%	5	6%	10	6%
TOTAL	69	100%	88	100%	157	100%

Twenty-two (32 percent) of the males and 49 (55 percent) of the females were considered treatable as opposed to 29 (forty-two percent) of the males and 16 (eighteen percent) of the females who were considered untreatable. Twenty percent of the total sample had a doubtful prognosis and seemed to be fairly evenly distributed between males and females as were the six percent with no prognosis given. The most outstanding thing this chart shows is the sharp difference between the percentage of males (32 percent) and females (55 percent) considered treatable,Almost a reversal is noted among those considered untreatable in that 29 (forty-two percent) of the males and 16 (eighteen percent) of the females fall in this category.

If we look at the age distribution (Table 4) we find that 63 percent of the males are over 70 years of age and 65 percent of the females are over 70 years of age. We might speculate then that either the females are more treatable or the males with treatable cataracts are more apt to get surgery than the women.

TABLE 4

AGE

AGE	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
1 - 19						
20- 29						
30- 39	1	1%	3	3%	4	2%
40- 49	3	4%	2	2%	5	3%
50- 59	7	10%	10	11%	17	11%
60- 69	15	22%	15	19%	30	20%
70- 79	24	35%	38	43%	62	39%
80/	19	28%	20	22%	39	25%
TOTAL	69	100%	88	100%	157	100%
	Median - 73.75		Median 73.68			
	Mean 71.66		Mean 71.25			

There were no cases under 30 years of age. Sixty-two (39 percent) of the sample were in the 70 -79 age group and 101 (64 percent) over 70 years of age. Only sixteen percent were below 60 years of age. There does not appear to be a great difference between the males and females in age distribution but it is interesting to note that 28 percent of the males were above 80 years of age as compared with 22 percent of the females.

Religion is distributed as follows: sixty-one (37 percent) Catholic, 35 (24 percent) Jewish, 52 (34 percent) Protestant and eight (five percent) other.

Race: 131 (84 percent) white and 26 (16 percent) Negro.

TABLE 5

MARITAL STATUS

	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
Married not living with spouse	2	3%	5	6%	7	5%
Married living with spouse	21	30%	13	15%	34	23%
Widowed	21	30%	49	55%	70	42%
Divorced	4	6%	1	1%	5	3%
Separated	5	7%	4	5%	9	6%
Single	16	24%	16	18%	32	21%
TOTAL	69	100%	88	100%	157	100%

In the total of those interviewed the largest percentage, 70 (42 percent) were widowed. Thirty-four (23 percent) were married and living with their spouse, while 32 (21 percent) were single. It may be noted that a much larger proportion (55 percent) of the females were widowed as compared to only 21 (30 percent) of the males. The fact that over 70 percent of all respondents are widowed, divorced, separated or single may have a bearing upon their adjustment to their blindness.

Of the 125 respondents who have been married, 87 (70 percent) have children who are living.

Social Data

TABLE 6

BIRTHPLACE

	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
United States	30	43%	47	53%	77	49%
Eastern Europe	12	17%	16	18%	28	18%
Western Europe	9	13%	14	16%	23	14%
Southern Europe	10	15%	2	2%	12	8%
Puerto Rico	3	5%	5	6%	8	6%
South America	2	3%	0	0%	2	1%
West Indies	2	3%	4	5%	6	4%
No answer	1	1%	0	0%	1	0%
TOTAL	69	100%	88	100%	157	100%

The largest percentage of the sample were born in the United States. This comprised 77 (49 percent) of the total; 28 (eighteen percent) were born in Eastern Europe. Twenty-three (fourteen percent) of the total were born in Western Europe (Germany, France, Netherlands, Britain, Ireland, etc.). Only twelve (eight percent) of the total were born in Southern Europe (Spain, Italy, Greece, etc.); eight (six percent) were born in Puerto Rico. The remainder came from the West Indies and South America. The distribution between the sexes seems quite even with the exception of those coming from Southern Europe (ten (fifteen percent) of the males and only two (two percent) of the females.) Thus the largest proportion of the sample is native born with 40 percent of the remainder coming from all areas of Europe.

Years of Residence in the United States: As indicated in Table 6, 77 (49 percent) of the sample are native born, with a somewhat greater proportion of females than males in this group. Nine (six percent) have been living in the United States less than ten years. Seven or a little more than 4% have been living here between ten-twenty years and the same number have been living here between 20-30 years. Fifty-six (36 percent) have been living here more than 30 years.

Years of Residence in New York City: One hundred thirty (82 percent) of the total sample were born in New York City or have lived in New York City over 30 years. The remaining 27 have lived in New York City between one and 30 years. One of the conjectures made in this study is that there are some people needlessly blind from senile cataracts because they failed to take advantage of available medical services. If a large percentage of our sample had rural backgrounds, it could be argued that the assumption of availability of medical services is questionable, however, such is not the case.

Citizenship: One hundred forty-three (91 percent) of the total sample are American citizens. Sixty-one (88 percent) of the males and 82 (93 percent) of the females are citizens. Only twelve (seven percent) are not citizens. The citizenship of two percent of the sample is not known. These figures include the native as well as the foreign born.

TABLE 7

EDUCATION

Years of Education	Males		Females		Total	
	No.	%	No.	%	No.	%
1 - 4	20	23%	26	30%	46	29%
5 - 8	26	47%	36	40%	62	40%
9 - 12	17	24%	20	23%	37	23%
13 and over	6	6%	6	7%	12	8%
TOTAL	69	100%	88	100%	157	100%

There is little appreciable or significant difference in the educational background between males and females. More than 90 percent never went beyond high school and almost 70 percent never went beyond grade school.

The low educational level of our sample could be expected in such an aged group. However, it (the low educational level) may have a bearing upon an understanding of diagnosis, treatment and their implications.

TABLE 8

MAJOR SOURCES OF INCOME

CLASSIFICATION	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
Employment	7	10%	1	1%	8	6%
Self Employment	2	2%			2	1%
DPW - AB	28	42%	41	47%	69	44%
OASI	8	13%	5	5%	13	9%
Private Pension	3	4%	5	5%	8	4%
Children	11	17%	19	25%	30	21%
Relatives	1	1%	5	5%	6	3%
Insurance	1	1%	1	1%	2	1%
Savings	3	4%	3	3%	6	4%
Spouse	3	4%	8	9%	11	7%
Other	1	1%			1	
No answer	1	1%			1	
TOTAL	9	100%	88	100%	157	100%

A total of seven percent derive their income from some kind of employment. A large percentage (44 percent) are receiving DPW AB assistance, which might be expected in view of the handicap and age range. Twenty-four percent were supported mainly by children and other relatives. There does not seem to be a significant difference in income source between male and female respondents. It is apparent that these people are living on a marginal income. It is reasonable to assume that this limits the type of medical services available to them. Further, it probably limits other services and mobility resulting in social isolation, etc.

TABLE 9

TYPE OF DWELLING

CLASSIFICATION	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
Private Home	9	13%	7	8%	16	10%
Apartment	34	49%	40	46%	74	47%
Nursing Home	10	15%	18	20%	28	18%
Boarding Home	2	3%	1	1%	3	2%
Home for Aged	5	7%	4	5%	9	6%
Rented or Hotel Room	9	13%	18	20%	27	17%
TOTAL	69	100%	88	100%	157	100%

The largest number of our total population (57 percent) live in apartments or private dwellings. Almost twice as many females as males live in hotels or rented rooms. The remaining 33 percent live in nursing homes, boarding homes or homes for the aged.

It would be reasonable to suppose that the people living in a nursing home (eighteen percent) or home for the aged (six percent) would be by virtue of physical debilitation and/or old age, poor risks for surgery, even if they had cataracts which were medically treatable. Further it could be conjectured in view of the residential availability of medical services that these people could not be classified as having treatable cataracts and not receiving treatment. However, our impression of the nursing homes visited would force us to be very guarded in assuming good medical services much less individualization.

TABLE 10

RESIDENCE STATUS OF 91 RESPONDENTS LIVING IN PRIVATE HOMES OR APARTMENTS

	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
Own Home	35	81%	31	65%	66	73%
Children's	4	9%	13	27%	17	18%
Relatives	2	5%	4	8%	6	6%
Friend's	2	5%	-	-	2	3%
TOTAL	43	100%	48	100%	91	100%

Seventy-three percent of all those living in private homes or apartments own or rent same. The balance are dependent on others. More females, thirteen (27 percent) live in their children's homes as compared to only four (nine percent) of the males.

Related to, but not shown, in Table 10 is the fact that although seventeen (eighteen percent) respondents live in their children's home 29 or almost one-third of the respondents live with their children.

Medical Data

TABLE 11

FIRST PERSON CONSULTED FOR HELP WITH EYE CONDITION

	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
Ophthamologist	59	85%	65	74%	124	79%
Optometrist	6	9%	15	18%	21	14%
Family Doctor	3	5%	4	4%	7	4%
Soc. or Welfare Agency	1	1%	3	3%	4	2%
Friend	-	-	-	-	-	-
Other	-	-	1	1%	1	1%
Unknown	-	-	-	-	-	-
TOTAL	69	100%	88	100%	157	100%

A large majority, 124 (79 percent) of the total population consulted an ophthamologist, either clinic or private, as their first contact. This might be explained to some extent by the fact that a large percentage of our population are financially dependent and thus would be more apt to use clinics for medical care.

The women seemed more inclined to consult an optometrist first than did the men.

TABLE 17

RELATIONSHIP BETWEEN LIVING ARRANGEMENTS AND DECISION TO UNDERGO EYE SURGERY

	LIVING WITH OTHERS		LIVING ALONE		TOTAL	
	No.	%	No.	%	No.	%
N*	36	51%	55	64%	91	58%
O*	35	49%	31	36%	66	42%
TOTAL	71	100%	86	100%	157	100%

* N - Not operated O - Operated

These findings would seem to indicate that people who live with others are more likely to have eye surgery than those who live alone. Forty-nine percent of those who live with others had operations, as compared to 36 percent of those living alone.

TABLE 18

RELATIONSHIP BETWEEN LIVING ARRANGEMENTS AND DECISION TO UNDERGO EYE SURGERY AMONG THE 71 RESPONDENTS DIAGNOSED "TREATABLE"

	LIVING WITH OTHERS		LIVING ALONE		TOTAL	
	No.	%	No.	%	No.	%
N*	15	51%	29	70%	44	62%
O*	14	49%	13	30%	27	38%
TOTAL	29	100%	42	100%	71	100%

* N - Not operated O - Operated

In the group with a prognosis of treatable, 49 percent of those living with others had eye surgery, in contrast to

30 percent of those living alone. The people living alone belong to a slightly higher age group, but age would not seem to account for the difference between those living alone and those living with others. The findings here and those which have been extracted from Table 17 show a similar pattern.

Years of Schooling

TABLE 19

RELATIONSHIP BETWEEN EDUCATION AND DECISION TO UNDERGO EYE SURGERY

	0 - 8		9 - 12		13 and over		Total	
	No.	%	No.	%	No.	%	No.	%
N*	65	59%	19	52%	7	64%	91	58%
O*	44	41%	18	48%	4	36%	66	42%
TOTAL	109	100%	37	100%	11	100%	157	100%

* N - Not Operated O - Operated

Educational level does not seem to have any bearing upon whether people had eye surgery or not. One of the intervening factors here is undoubtedly age. Older people could be expected to have less education than younger people in our population.

TABLE 20

RELATIONSHIP BETWEEN ADJUSTMENT AND DECISION TO UNDERGO EYE SURGERY AMONG 33 RESPONDENTS DIAGNOSED AS "TREATABLE"

	GOOD		AVERAGE		POOR		TOTAL	
	No.	%	No.	%	No.	%	No.	%
N*	1	33%	9	60%	12	80%	22	67%
O*	2	67%	6	40%	3	20%	11	33%
TOTAL	3	100%	15	100%	15	100%	33	100%

* N - Not Operated O - Operated

TABLE 20A

	GOOD AND AVERAGE		POOR		TOTAL	
	No.	%	No.	%	No.	%
N*	10	56%	12	80%	22	67%
O*	8	44%	3	20%	11	33%
TOTAL	18	100%	15	100%	33	100%

* N-Not operated O - Operated

The respondent's adaptation to and attitudes toward his visual difficulty, his attitudes toward his family and sighted people and his own self picture were seen as being relevant to his behavior viz-a-viz his decision to undergo surgery. The device utilized to get at this, was a group of questions (see questionnaire questions 49-60, Appendix I) borrowed directly or adapted from "Evaluation of Adjustment to Blindness" by Edward A. Fitting, published by the American Foundation for the Blind, Vol. No. 2. 1954. The

questions selected were those which discriminated most significantly and consistently between the poorly and well adjusted.

Our experience was not wholly satisfactory in administering these questions. Fifty-two percent of our total population responded to all of these questions, 30 percent answered some and we were not able to elicit any answers from eighteen percent. Where agreement or disagreement indicated good adjustment it was scored ten; where it indicated poor adjustment it was scored twenty. Thus, maximum good adjustment would score 120 and minimum or poor adjustment was 240. A score of up to 130 was regarded as good adjustment, 140 - 160 was average, 170 and over was poor.

Tables 20 and 20A show as indicated, the distribution only for those people 33 out of 71 in the treatable prognosis group who answered all the questions. The findings presented in these tables seem to indicate that those people with good and average adjustments are more likely to seek eye surgery than those with poor adjustments. However the total size of this group answering all the questions, and the number of cases in some of the cells, renders the drawing of inferences from the tables a very risky business.

If we had a much larger number of cases answering all the questions and they followed the pattern in the foregoing tables, we could with much greater comfort assert a relationship between the degree of adjustment and decision to undergo surgery. In any case the findings are suggestive and justifies further study.

TABLE 21

RESPONSES BY 91 PERSONS WHO DID NOT HAVE SURGERY TO THE QUESTION: "ARE YOU PLANNING TO HAVE SURGERY?"

REPLY	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
Yes	4	11%	7	13%	11	12%
No	21	58%	34	62%	55	60%
No Response	11	31%	14	25%	25	28%
TOTAL	36	100%	55	100%	91	100%

In the light of the presumption of high operability of the senile cataract, it is significant that only twelve percent of the group who have not had surgery plan to have it and 60 percent do not. It is believed that a large percentage of the no response group do not intend to have surgery. There is no significant difference between the male and female responses.

TABLE 22

TIME INTERVAL BETWEEN ONSET OF VISUAL DIFFICULTY AND FIRST MEDICAL CONTACT

TIME INTERVAL	NO.	PERCENT
Within 1 month	56	36%
Within 3 months	27	17%
Within 6 months	21	13%
Within 1 year	19	12%
Within 18 months	3	2%
Within 2 years	4	3%
Within 3 - 5 years	8	5%
After 5 years	8	5%
No Response	11	7%
TOTAL	157	100%

TABLE 22 A

TIME INTERVAL BETWEEN ONSET OF VISUAL DIFFICULTY AND LAST MEDICAL CONTACT

TIME INTERVAL	NO.	PERCENT
1 - 3 months	5	3%
3 - 6 months	10	6%
6 mo. - 1 year	11	7%
1 - 3 years	30	19%
4 - 6 years	22	14%
7 years & over	52	34%
No Response	27	17%
TOTAL	157	100%

The fact that 123 people report their first medical contact to be one year after onset of visual difficulty, should be viewed guardedly for the following reasons: 1) the process of developing opacities of the lens is a slow one, 2) it is difficult to recall such information with accuracy, and 3) the awareness of eye difficulty varies with individual factors. What is perhaps more significant is the fact that twenty persons delayed seeking medical help for a period ranging from one to more than five years from the onset of the reported eye difficulty.

In most cases (Table 22A) the last medical contact is equivalent to the year of registry and for some it is after registry. Consequently, it is interesting to note that 48%, almost half of the respondents, have been involved with medical services for a period ranging from four to more than nine years without any apparent medical success. It should also be noted that seventeen percent of the respondents were not able to recall their last medical contact.

Attitudes and Perceptions Related to Visual Difficulty

TABLE 23

RESPONSES TO QUESTION: "WHAT DO YOU THINK IS WRONG WITH YOUR EYES?"

DIAGNOSIS	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
Cataracts	50	72%	56	64%	106	68%
Medical Complications other than eye trouble	1	1%	4	4%	5	3%
Glaucoma and/or other eye diseases	4	6%	12	14%	16	10%
Don't Know	9	13%	11	12%	20	13%
Other	5	7%	5	6%	10	6%
TOTAL	69	99%	88	100%	157	100%

Sixty-eight percent of the sample described their condition in one way or another as cataracts. It must be noted however that some of these people also felt that they had other conditions such as glaucoma or other health conditions which complicated the cataracts. Ten percent described their condition as being glaucoma and/or other eye disease and these too sometimes had secondary debilitating physical conditions. Thirteen percent seemed to have no clear conception of their condition.

A greater proportion of men (72 percent) than women (64 percent) described their condition as cataracts. Also fourteen percent of the women feel that they have glaucoma while only six percent of the men gave this response.

TABLE 24

RESPONSES BY THOSE WHO DID NOT HAVE SURGERY TO THE QUESTION: "DO YOU THINK SURGERY WOULD HELP YOU?"

	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
Yes	7	19%	14	25%	21	23%
No	12	33%	22	40%	34	37%
No Response	17	48%	19	34%	36	40%
TOTAL	36	100%	55	100%	91	100%

Among the respondents who did not have eye surgery, we find that 23 percent feel that surgery would help them whereas 37 percent do not feel that they would benefit by surgery. Forty percent did not respond and this includes a large number of people who did not know if surgery would help or not. If this were broken down according to prognosis, we might have a better idea as to how many of these people

might actually be helped by surgery.

Table 21 indicates that twelve percent of this same group of 91 persons are planning to have surgery, but 23 percent believe that surgery would help them. This raises the question of why a fewer number of persons plans to have surgery than think that surgery would help them.

On the supposition that knowledge about other people who had had eye surgery would affect attitudes toward surgery, we asked the interviewees whether they knew such people and if so what was the outcome of surgery.

We found that only 55 interviewees knew anyone who had had eye surgery. Of these 53 percent of the persons known have allegedly had successful surgery and 35 percent unsuccessful surgery. Some respondents (twelve percent) had known people to have both successful and unsuccessful surgery.

Similarly we thought that misconceptions among those who had not had surgery about the nature of medical procedures, length of hospitalization, costs, etc., would affect attitudes toward eye surgery. The two tables which follow bear upon this conjecture.

TABLE 25

ESTIMATED LENGTH OF HOSPITAL STAY BY THOSE RESPONDENTS WHO DID NOT HAVE SURGERY.

LENGTH OF STAY	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
1 day - 1 week	3	8%	3	5%	6	7%
8 - 14 days	8	22%	9	16%	17	19%
14 - 30 days	4	12%	7	13%	11	12%
31 days - 3 mos.	3	8%	2	4%	5	5%
No Response	18	50%	34	62%	52	57%
TOTAL	36	100%	55	100%	91	100%

A majority, 57 percent of the respondents interviewed, did not respond to the question pertaining to estimated length of hospital stay. These were the people by and large who did not know how long the stay would be and would not estimate. Nineteen percent of the group estimated the length of stay to be eight to fourteen days. The significant point seems to be in the large number of persons who do not seem to be at all informed on how long they must stay in the hospital following surgery. Since a large proportion of our respondents were clinic patients we wonder if this aspect is discussed with them in the clinic.

TABLE 26

ESTIMATED COST OF SURGERY BY THOSE RESPONDENTS WHO DID NOT HAVE SURGERY

COST	MALE		FEMALE		TOTAL	
	No.	%	No.	%	No.	%
0 - $199	4	11%	5	9%	9	10%
$200 - $299	2	6%	2	4%	4	4%
$300 - $399	3	8%	3	5%	6	6%
$400 - $599	2	6%	2	4%	4	4%
$600 - $1000	1	3%	-	-	1	2%
Don't Know	14	36%	29	53%	43	47%
No Response	11	30%	14	25%	25	27%
TOTAL	37	100%	55	100%	91	100%

Of the respondents interviewed who had not had any surgery 47 percent were not able to make an estimate as to the cost of surgery. Twenty-seven percent did not respond to the question at all, ten percent estimated the cost as

between
being/$1.00 and $199. The rest were distributed among the higher amounts. Here again we find evidence that people are not well informed in matters relevant to their visual difficulty.

The "Treatable" Group

The following tables represent an attempt to more specifically elaborate variables relevant to the treatable group of 71 persons who have been so classified according to the State Commission records.

Specific concern with this group is justified for obvious reasons: Presumptions of inadequate medical care and other factors interfering with treatment would, if indicated, have immediate bearing for action directed toward mitigating unnecessary blindness.

TABLE 27

AGE: "TREATABLE" GROUP

	MALE	FEMALE	TOTAL
	No.	No.	No.
Under 50	3	1	4
50- 60	2	7	9
60- 70	4	11	15
70- 80	7	16	23
80 and over	6	14	20
TOTAL	22	49	71
Mean 70.0	Median 72.9	Mean 72.5	Median 73.7

The age distribution for the "Treatable" group is similar to the entire group.The mean for the men in this group is slightly lower than in the total group, and the median is slightly higher. The mean age for women in this group is

slightly higher than in the entire group, the median age is the same.

TABLE 28

TREATMENT RECOMMENDED: "TREATABLE" GROUP

	MEN	WOMEN	TOTAL
	No.	No.	No.
Surgery	18	39	57
No Recommendation	3	7	10
Other	1	3	4
TOTAL	22	49	71

Fifty-seven (&0 percent) out of 71 in the treatable group had surgery recommended. This information was taken from interviews and not from medical records.

TABLE 29

TREATMENT DECISION BY "TREATABLE" GROUP FOLLOWING MEDICAL RECOMMENDATION

	MALE		FEMALE		TOTAL
Recommendation	yes	no	yes	no	
Surgery	10	8	17	22	57
Other	1	0	2	1	4
TOTAL	11	8	19	23	61*

* No recommendation was made for three men and seven women.

The significant thing in this table is that 27 out of 57 for whom surgery was recommended underwent surgery. The reasons for the 30 not following the recommendation of surgery are suggested in the next table.

TABLE 30

REASONS GIVEN BY THIRTY "TREATABLES" FOR NOT FOLLOWING RECOMMENDED SURGERY

	MALE	FEMALE	TOTAL
Age and other debilitating factors	2	3	5
Fear	4	13	17
Family Resistance	1	1	2
Misunderstanding of Condition	0	1	1
Financial	1	1	2
Temporary Illness other than eye	0	3	3
TOTAL	8	22	30

If we assume the validity of the data in the above table and the reliability of our interviewers the suggestion is very strong that fear prevents many people from seeking surgery.

TABLE 31

TIME SPAN BETWEEN ONSET OF VISUAL DIFFICULTY AND REGISTRY FOR "TREATABLE" GROUP

	MALE	FEMALE	TOTAL
	No.	No.	No.
Up to 1 year	5	5	10
1 - 2 years	1	3	4
2 - 3 years	3	5	8
3 - 5 years	4	14	18
5 - 10 years	4	13	17
10 years & over	5	9	14
TOTAL	22	49	71

About 70 percent of the "treatables" report the onset of eye difficulty as being three or more years before registration with the State Commission for the Blind.

TABLE 32

TIME OF LAST SURGERY FOR 27 "TREATABLES" WHO UNDERWENT SURGERY

	MALE	FEMALE	TOTAL
Prior to Registration	6	12	18
Following Registration	4	5	9
TOTAL	10	17	27

Examination of Table 32 suggests that the nine out of the 27 who were operated on following registration may no longer belong in the registry.

The "Untreatable" Group

The following tables elaborate some variables with respect to 44 people who were classified as "untreatable" according to information in the files at the New York State Commission for the Blind.

TABLE 33

AGE: "UNTREATABLE" GROUP

	MALE	FEMALE	TOTAL
Under 50	0	1	1
50 - 60	3	2	5
60 - 70	6	5	11
70 - 80	13	5	18
80 and over	6	3	9
TOTAL	28	16	44

The age distribution here is similar to that of the entire group.

TABLE 34

REASONS GIVEN FOR "UNTREATABLE" STATUS

	MALE	FEMALE	TOTAL
Previous Surgery Unsuccessful	12	6	18
Improved Vision	5	3	8
Eye Complications	4	1	5
Other Medical Complications	4	1	5
Awaiting Surgery	0	1	1
Don't Know	3	4	7
TOTAL	28	16	44

Over half of the respondents considered not treatable were so because of either unsuccessful surgery or because they had had the necessary surgery which resulted in improved vision and no further improvement could be anticipated.

TABLE 35

TIME OF LAST SURGERY FOR 26 "UNTREATABLES" WHO UNDERWENT SURGERY

	MALE	FEMALE	TOTAL
Surgery Prior to Registration	14	7	21
Surgery after Registration	3	2	5
TOTAL	17	9	26

Almost half of this group had surgery prior to registration with the State Commission for the Blind which would indicate (since these people are now considered untreatable) that this surgery was unsuccessful. It is also interesting to note that over half the people considered untreatable did receive surgery at one time or another. Since the total "untreatable" group numbers 44 the remaining eighteen (eleven men, seven women) had not undergone surgery at time of interview.

CHAPTER V.

SUMMARY OF FINDINGS AND IMPLICATIONS

Findings:

Forty-four percent of the 157 respondents interviewed were males; 56 percent were females. Eighty-four percent were White and sixteen percent Negro. Thirty-seven percent were Catholic, 34 percent Protestant, 24 percent Jewish, and five percent members of other religious groups.

Forty-four percent of the respondents were considered treatable, 30 percent were considered untreatable, twenty percent doubtful, and six percent were given no prognosis, according to information in the files of the State Commission for the Blind.

Eighty-four percent of the respondents were sixty years of age or older. None were younger than thirty years of age. Men and women seem to be distributed equally over the age range.

Forty-two percent of the respondents were widowed, 23 percent were married and living with their spouse, and 21 percent were single.

About half of those interviewed were born in the United States and about 35 percent more have been living in the United States more than thirty years.

The educational level is low. Almost 70 percent of the group interviewed had no education beyond grammar school.

Only ten persons in our sample were employed. Forty-four percent were receiving some form of public assistance. Twenty-four percent received their major income from relatives and children. Thirteen percent were receiving income from OASI.

Forty-seven percent of the respondents live in apartments; ten percent live in private homes; 26 percent live in nursing homes, boarding homes or old age homes.

Seventy-nine percent of the respondents consulted an ophthalmologist (either privately or in clinic) first. Only four percent first consulted the family physician. Fourteen percent of the women first consulted an optometrist. More than half of the group used the clinic only and an additional seventeen percent used a clinic prior to or following use of a private physician.

The data indicates a direct relationship between age and the decision to undergo eye surgery. The lower the age of the respondents, the higher the proportion who undergo surgery.

Proportionately more men undergo eye surgery than women.

Race and religious background do not seem to be related to the decision to accept or reject eye surgery.

There is a seeming relationship between an individual's living alone or with family and/or friends, and his decision to undergo eye surgery. A higher proportion of those living with others have had operations than those living alone.

There is a slight seeming relationship between education and decision to undergo surgery, (e.g. the more educated are slightly more likely to undergo surgery) but this is to be taken guardedly and is subject to further examination.

There is some relationship between decision to undergo surgery and "adjustment", (e.g. the better "adjusted" are more likely to undergo surgery than the poorer "adjusted"). However, for reasons indicated in the previous chapter the findings must be viewed very cautiously and tentatively.

Twelve percent of the 91 persons who did not have surgery planned to do so in the future.

Twenty-three of the 91 not operated on thought surgery could help them. The remainder made no response, or did not feel or know if surgery would help.

Among the 71 "treatable", the following are significant findings: The age distribution is similar to the rest of the sample. Surgery was recommended in 80 percent of the treatable cases; however, less than half followed the recommendation. The remaining group gave a number of reasons for not undergoing surgery, the most striking of which was fear.

Of the 44 "untreatable", the following are significant findings: The age distribution is similar to the rest of the sample. Over half of the "untreatables" had successful previous surgery or vision was improved to the maximum from previous surgery. A large percentage of the "untreatables" had surgery prior to registration with the State Commission for the Blind.

Implications:

The discussion which follows is based on the reported findings, our knowledge as social workers, and on our experience in interviewing our sample. Some interview material could not be assembled or be reflected in statistical tables, however, these were included in summaries attached to each questionnaire.

Suggested areas for further study include: 1) a follow up study, comparing two groups: operated upon and not operated

upon despite a recommendation and favorable prognosis, 2) an analysis of the relationship between accepting or rejecting surgery and the individual's previous experiences with eye surgery. 3) an analysis of the reasons for the higher proportion of males who underwent surgery. We assume that one of the factors operating is that society places a higher degree of responsibility (for support of his family or of himself) and a higher demand for independence upon males.

Our findings regarding the relationship between undergoing surgery and an individual's actual living arrangements (alone or with family or friends) would suggest a need to develop a program of special services for those living "alone". Such a program might include transportation to and from physicians, clinics, agencies for the blind, etc. Our impression is that the absence of such services and the absence of personal encouragement is an important factor in producing attitudes of resignation, despair and indifference. In this respect it should be noted that a large proportion of people sought medical help within the first month, and an even greater number within the first year after noticing the first symptoms of eye trouble. Therefore, at the point when they noticed deteriorating vision they were basically interested in securing medical help. Many people who did not undergo surgery did not do so because of fear.An even larger number did not seem to understand what was involved in their illness. Some might have been frightened by their first medical contact and may have stopped going to a doctor; others might have consulted a succession of other physicians.

Even though some individuals were too fearful to follow the physician's recommendation to have surgery, and others did not trust the original diagnosis and recommendation of the doctor, we were struck by the fact, that many of our respondents were confused about possible treatment, did not understand the medical diagnosis at all and therefore lost valuable time in making any decision to undergo treatment.

It appears that often there occurs "a breakdown of communication" between physician and his patient. It is possible that medical ethics would inhibit the doctor from "persuading" the patient to undergo surgery. Also his lack of knowledge of the patient's social circumstances and personality structure might also be limiting factors. Therefore, thought ought to be given to providing other means (medical social services) of "professional interpretation" to the patient.

Our study shows that the lower the age the more likely a person will actually undergo cataract surgery. However, we also learned that more than one-third of those who did undergo surgery were 70 years old and older. From the content of our interviews it appears that the older group of people suffering from senile cataracts is not sufficiently aware of the fact that they too can benefit from surgery. They have a greater need for counselling, support and encouragement to undergo surgery. The people in our study have many and complex problems, of which the cataract condition and the resulting blindness is only one, albeit the crucial one. The ophthalmologist cannot be expected, nor has he the special training required to deal with and to "treat" these patients' "total ills". Yet, in order to really meet their specific problems they must be looked upon as total "people" with all their complexities.

On the basis of our experience we feel, that often the reluctance to get medical help or to accept the recommendation for cataract surgery can be traced to a tendency on the part of those who are helpers to separate the specific medical problem from the total interacting person who has a medical problem. Therefore, the development of a program of education to encourage older people to have an operation, if such is recommended by the ophthalmologist, is urgently needed. We also see a need for strengthening existing social services.

In view of the shortage of trained social workers, the training of volunteers could be considered for such functions as paying regular visits to the isolated and socially deprived blind. This would supply social contacts, etc. and will give the blind an opportunity to discuss their concerns and to receive encouragement and support. Such services could help implement any educational program geared to people suffering form senile cataracts.

APPENDIX I

CATARACT PROJECT
INTERVIEW GUIDE

1. NAME _____
   Last First Middle

2. AGE

1-19	20-29	30-39	40-49	50-59	60-64	65-69	70-74	75-79	80 +

3. Are you
   Married 1___, widowed 2___, divorced 3_____, separated 4___
   single 5_____

4. (If married ask) Are you living with your husband (wife?)
   Yes _____ No _____

5. (If answer to #3 was married, divorced, separated or widowed ask)
   When were you
   Married _____, divorced _____, separated _____, widowed___

6. Where were you born? _____

7. Are you an American citizen? Yes _____ No _____

8. How many years have you lived in this country?
   _____1. born here
   _____2. under five years
   _____3. 5 - 10 years
   _____4. 10 - 20 years
   _____5. 20 -30 years
   _____6. Over 30 years

9. How many years have you lived in New York City?
   _____1. born here
   _____2. under five years
   _____3. 5- 10 years
   _____4. 10 - 20 years
   _____5. 20 - 30 years
   _____6. Over 30 years

10. (Ask only of those born in the United States)
    Where were your parents born? Mother _____ Father _____

11. (Interviewer, check type of dwelling)
    _____ 1. private home - No. of Rooms _____
    _____ 2. Apartment - No. of Rooms _____
    _____ 3. Institution for the Blind
    _____ 4. Nursing Home
    _____ 5. Boarding Home
    _____ 6. Old Age Home
    _____ 7. Rented or Hotel Room

12. Do you have any children? Yes _____ No ____

65

13-18 IF INTERVIEWER HAS CHILDREN, FILL IN THE FOLLOWING CHART INDICATING: AGE, SEX OF CHILDREN, WHETHER THEY ARE LIVING AT HOME, AND EMPLOYMENT STATUS.

	AGE	SEX	LIVING AT HOME YES	LIVING AT HOME NO	EMPLOYED YES	EMPLOYED NO
1.						
2.						
3.						
4.						
5.						
6						

19 IF PRIVATE HOME OR APARTMENT ASK:
Whose home is this?

_____ 1. Own
_____ 2. Childrens
_____ 3. Relatives
_____ 4. Friends

19a. FILL IN THE FOLLOWING CHART WHEN THERE ARE PERSONS OTHER THAN THE SPOUSE AND/OR CHILDREN LIVING IN THE HOME.

1	AGE	SEX	RELATIONSHIP	EMPLOYMENT
2.				
3.				
4.				
5.				

20. How much schooling have you had? CIRCLE ONE

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15

16 16+

21. ASK OF ALL INTERVIEWERS:
What is your MAJOR source of income? (CHECK ALL CATAGORIES THAT APPLY)

_____1. employment
_____2. Self employment
_____3. DPW AB
_____4. DPW OASI
_____5. Private Pension
_____6. Children
_____7. Relatives
_____8. Insurance
_____9. Savings
_____10. Spouse
_____
_____

22. What is your present occupation ?

_____ Write in

_____ Unemployed

_____ Retired

23. IF EMPLOYED ASK:
Is this the same kind of work you did before your visual difficulty? YES _____ NO_____

24. IF INTERVIEWEE IS NOW RETIRED OR UNEMPLOYED OR HAS CHANGED OCCUPATIONS SINCE HIS VISUAL DIFFICULTY ASK:
What was your former occupation?

_____

_____

_____

25. How do you travel?

_____1. Alone

_____2. Cane

_____3. Dog

_____4. Guide

_____5. Other

26. For what purposes do you travel?

_____ 1. Work

_____ 2. Recreation

_____ 3. Services

_____ 4. Other

27. How often do you travel and what facilities do you use?

PURPOSE	FREQUENCY*	FACILITY*
WORK		
RECREATION		
SERVICES		
VISITING		

*Definition of terms for interviewer:

Frequency: (1) Daily (2) 1 or 2 times a week (3) 1 or 2 times a month (4) rarely

Facility: (1) Walk (2) bus (3) Subway) 4 Taxi (5) private car

28. When did your present eye trouble begin?

_____

_____

_____

_____

_____

29. What were some of the signs of difficulty and when did they first begin?

TYPE	ONSET
Blurring of vision	
Double Vision	
Inability to see complete object	
Black spot	
Other	

30. When did you first go for help after you noticed your present eye trouble?

_____ 1. within first month
_____ 2. within three months
_____ 3. within six months
_____ 4. within first year
_____ 5. within eighteen months
_____ 6. within two years
_____ 7. within three to five years
_____ 8. after five years

31. To whom did you first go for help with your present eye condition?

	* Name	*Address
_____1. Opthamologist or occulist		
_____2. Optometrist		
_____3. Family Physician		
_____4. Clinic		
_____5. Social or Welfare Agency		
_____6. Friend		
_____7. Other		

*Does not apply to 6 and 7.

32. This was the 1 2 3 4 5 6 person consulted. 69

(If the answer to #31 was other than opthalmologist or occulist turn to page 7 question # 36

(If the answer to #31 was opthalmologist or occulist ask the following:

What did Dr. _____ say to you?

_____

_____

_____

_____

_____

32A. Was it treatable? Yes _____ No _____
(If not treatable skip to #34) (If treatable, ask)

32B. What was the treatment recommended?

_____

_____

_____

32C. When did the Doctor suggest you begin treatment? _____

32D. What did your family advise you to do? _____

_____

_____

_____

33. Did you follow the Doctor's recommendation? Yes ____ No _____

If YES Ask:

33A. When did you start treatment. _____

33B. What was the outcome of this Treatment _____

_____

_____

_____ 1. Improvement
_____ 2. No improvement

33C. Did you seek further help?
Yes _____ No _____

(If answer to #33C is no turn to top of 8 question #38 and complete interview)

If NO Ask:

33F. Why didn't you follow this Dr. recommendation?

_____

_____

_____

_____

_____1 financial difficulty
_____2 family didn't approve
_____3 disbelief in Dr. and/or recommendations.
_____4 afraid of hospitalization 6
_____5 afraid of surgery
_____6 afraid of treatment
_____7 didn't understand

33C (continued)
If yes to #33C ask:)

33D How long did you wait before going for this help? _____

33E. To whom did you go for help?
_____1. opthalmologist or
_____2. occulist
_____3. family doctor
_____44 hospital or clinic
_____5. social welfare agency
_____6. friend
_____7. other

(If answer is #1 continue on next page)

If answer is # 2- 7 turn to p.7.

33G. Did you go to anyone else after Dr. _____ for your present eye condition?
Yes _____ No _____
(If answer is No, turn to p.8 question #38)
(If answer is yes, ask:)

33H. How long did you wait before going to another person? _____

33I. To whom did you go for help?

_____1.opthalmologist or occulist
_____2.optometrist
_____3.family doctor
_____4.hospital or clinic
_____5.social or welfare agency
_____6.friend
_____7.other

(If answer is #1 continue on next page)
(If answer is #2-7 turn to p.7)

(If not treatable, ask:)

34. Why was your condition untreatable?

_____

_____

_____

_____

_____

35. Did you go to anyone else after Dr._____ for help with your present eye condition? Yes _____ No _____

Yes	No
35A. How long did you wait before going to another person _____	No further questions _
35B. To whom did you go for help? _____1 opthamologist or occulist _____2 optometrist _____3 family doctor _____4 hospital or clinic _____5 social or welfare agency _____6 friend _____7 other (If answer was #1, continue on next page)	Turn to p8, question #38 and procede with interview

32. This was the 1 2 3 4 5 6 person consulted.

(If the answer to #31 was other than opthalmologist or occulist turn to page 7 question # 36

(If the answer to #31 was opthalmologist or occulist ask the following:

What did Dr. _____ say to you?

_____

_____

_____

_____

_____

32A. Was it treatable? Yes _____ No _____
(If not treatable skip to #34) (If treatable, ask)

32B. What was the treatment recommended?

_____

_____

_____

32C. When did the Doctor suggest you begin treatment? _____

32D. What did your family advise you to do? _____

_____

_____

_____

33. Did you follow the Doctor's recommendation? Yes ____ No _____

If YES Ask:

33A. When did you start treatment. _____

33B. What was the outcome of this Treatment _____

_____

_____

_____ 1. Improvement
_____ 2. No improvement

33C. Did you seek further help?
Yes _____ No _____

(If answer to #33C is no turn to top of 8 question #38 and complete interview)

If NO Ask:

33F. Why didn't you follow this Dr. recommendation?

_____

_____

_____

_____

_____1 financial difficulty
_____2 family didn't approve
_____3 disbelief in Dr.and/or recommendations.
_____4 afraid of hospitalization 6
_____5 afraid of surgery
_____6 afraid of treatment
_____7 didn't understand

33C (continued)
If yes to #33C ask:)

33D How long did you wait before going for this help? _____

33E. To whom did you go for help?
____1. opthalmologist or
____2. occulist
____3. family doctor
____44 hospital or clinic
____5. social welfare agency
____6. friend
____7. other

(If answer is #1 continue on next page)

If answer is # 2- 7 turn to p.7.

33G. Did you go to anyone else after Dr. _____ for your present eye condition?
Yes _____ No _____
(If answer is No, turn to p.8 question #38)
(If answer is yes, ask:)

33H. How long did you wait before going to another person? _____

33I. To whom did you go for help?

____1.opthalmologist or occulist
____2.optometrist
____3.family doctor
____4.hospital or clinic
____5.social or welfare agency
____6.friend
____7.other

(If answer is #1 continue on next page)
(If answer is #2-7 turn to p.7)

(If not treatable, ask:)

34. Why was your condition untreatable?

_____

_____

_____

_____

_____

35. Did you go to anyone else after Dr._____ for help with your present eye condition? Yes _____ No _____

Yes	No
35A. How long did you wait before going to another person _____	No further questions _
35B. To whom did you go for help? _____1 opthamologist or occulist _____2 optometrist _____3 family doctor _____4 hospital or clinic _____5 social or welfare agency _____6 friend _____7 other	Turn to p8, question #38 and procede with interview

(If answer was #1, continue on next page)
(If answer is #2-7 turn to p.7.

32. This was the 1 2 3 4 5 6 person consulted.

(If the answer to #31 was other than opthalmologist or occulist turn to page 7 question # 36

(If the answer to #31 was opthalmologist or occulist ask the following:

What did Dr. _____ say to you?

_____

_____

_____

_____

_____

32A. Was it treatable? Yes _____ No _____
(If not treatable skip to #34) (If treatable, ask)

32B. What was the treatment recommended?

_____

_____

_____

32C. When did the Doctor suggest you begin treatment? _____

32D. What did your family advise you to do? _____

_____

_____

_____

33. Did you follow the Doctor's recommendation? Yes ____ No _____

If YES Ask:

33A. When did you start treatment. _____

33B. What was the outcome of this Treatment _____

_____

_____

_____ 1. Improvement
_____ 2. No improvement

33C. Did you seek further help?
Yes _____ No _____

(If answer to #33C is no turn to top of 8 question #38 and complete interview)

If NO Ask:

33F. Why didn't you follow this Dr. recommendation?

_____

_____

_____

_____

_____1 financial difficulty
_____2 family didn't approve
_____3 disbelief in Dr.and/or recommendations.
_____4 afraid of hospitalization 6
_____5 afraid of surgery
_____6 afraid of treatment
_____7 didn't understand

33C (continued)
If yes to #33C ask:)

33D How long did you wait before going for this help? _____

33E. To whom did you go for help?
____1. opthalmologist or
____2. occulist
____3. family doctor
____44 hospital or clinic
____5. social welfare agency
____6. friend
____7. other

(If answer is #1 continue on next page)

If answer is # 2- 7 turn to p.7.

33G. Did you go to anyone else after Dr. _____ for your present eye condition?
Yes _____ No _____
(If answer is No, turn to p.8 question #38)
(If answer is yes, ask:)

33H. How long did you wait before going to another person? _____

33I. To whom did you go for help

____1.opthalmologist or occulist
____2.optometrist
____3.family doctor
____4.hospital or clinic
____5.social or welfare agency
____6.friend
____7.other

(If answer is #1 continue on next page)
(If answer is #2-7 turn to p.7)

(If not treatable, ask:)

34. Why was your condition untreatable?

_____

_____

_____

_____

_____

35. Did you go to anyone else after Dr._____ for help with your present eye condition? Yes _____ No _____

Yes	No
35A. How long did you wait before going to another person _____	No further questions _
35B. To whom did you go for help? _____1 opthamologist or occulist _____2 optometrist _____3 family doctor _____4 hospital or clinic _____5 social or welfare agency _____6 friend _____7 other	Turn to p8, question #38 and procede with interview

(If answer was #1, continue on next page)
(If answer is #2-7 turn to p.7.

36. This was the 1 2 3 4 5 6 person consulted

If answer to #31 was 2. optometrist 5. social or welfare agency
3. family doctor 6 friend
4. clinic or hospital 7 other

omit #32 -#35 and ask:

What did the person tell you?

_____
_____
_____
_____
_____

36A. Did you follow this person's recommendations? Yes ____ No ____

36B. What did your family advise you to do?

_____
_____
_____
_____
_____

36C Did you go to anyone else after this person for help with your present eye condition?

Yes_____ No _____

(If answer to #36C was Yes ask:) (If answer is no turn to p.8 #38

37. To whom did you go for help?

_____1. opthalmologist or occulist
_____2. optometrist
_____3. family doctor
_____4. clinic or hospital
_____5. social or welfare agency
_____6. friend
_____7. other

(If answer was # 1 turn back to page 6)

(If answer was # 2-7 turn to next page)

36. This was the 1 2 3 4 5 6 person consulted

If answer to #31 was 2. optometrist 5. social or welfare agency
3. family doctor 6 friend
4. clinic or hospital 7 other

omit #32 -#35 and ask:

What did the person tell you?

_____
_____
_____
_____
_____

36A. Did you follow this person's recommendations? Yes ____ No ____

36B. What did your family advise you to do?

_____
_____
_____
_____
_____

36C Did you go to anyone else after this person for help with your present eye condition?

Yes_____ No _____

(If answer to #36C was Yes ask:) (If answer is no turn to p.8 #38

37. To whom did you go for help?

_____1. opthalmologist or occulist
_____2. optometrist
_____3. family doctor
_____4. clinic or hospital
_____5. social or welfare agency
_____6. friend
_____7. other

(If answer was # 1 turn back to page 6)

(If answer was # 2-7 turn to next page)

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36. This was the 1 2 3 4 5 6 person consulted

If answer to #31 was 2. optometrist 5. social or welfare agency
3. family doctor 6 friend
4. clinic or hospital 7 other

omit #32 -#35 and ask:

What did the person tell you?

_____
_____
_____
_____
_____

36A. Did you follow this person's recommendations? Yes ____ No ____

36B. What did your family advise you to do?

_____
_____
_____
_____
_____

36C Did you go to anyone else after this person for help with your present eye condition?

Yes_____ No _____

(If answer to #36C was Yes ask:) (If answer is no turn to p.8 #38

37. To whom did you go for help?

_____1. opthalmologist or occulist
_____2. optometrist
_____3. family doctor
_____4. clinic or hospital
_____5. social or welfare agency
_____6. friend
_____7. other

(If answer was # 1 turn back to page 6)

(If answer was # 2-7 turn to next page)

38. What do you think is wrong with your eyes?

_____

_____

_____

39. Are you covered by

_____ 1. Blue Cross (Hospitalization)

_____ 2. Blue Shield (Surgical)

_____ 3. H.I.P

_____ 4. Private Medical Insurance

_____ 5. Other

_____ 6. No coverage

40. Do you know anyone who was operated on because of eye trouble (cataracts)?

Yes _____ No _____

If #40 was answered yes, ask:)

41. Who? 1. _____

2. _____

3. _____

42. What was the outcome? 1. _____

2. _____

3. _____

(Ask questions #43 -#47 only of those who have not been operated upon)

43. How much do you think an operation would cost? $ _____

44. How long do you think you would have to stay in the hospital if you had an operation? _____

45. Do you think an operation would help you? Yes _____ No _____

46. Are you planning to have an operation? Yes _____ No _____

If answer to #46 is yes, ask:

47. When are you planning tohave the operation? _____

_____

48. Have you ever been hospitalized for other than eye trouble?
YES _____ NO _____

THE FOLLOWING ARE STATEMENTS OF OPINION. THEY MAY OR MAY NOT REFER TO PROBLEMS OF THOSE WITH VISUAL DIFFICULTIES. WE WOULD LIKE THE OPINION OF EACH INTERVIEWEE AS TO WHETHER THEY AGREE OR DISAGREE WITH EACH STATEMENT.

49. life is just one worrry after another in these times.
Agree _____ Disagree _____

50. No one cares much what happens to you.
Agree _____ Disagree _____

51. Because they know each others' problems better, the blind can put their trust in other handicapped people more than those who are not handicapped.
Agree _____ Disagree _____

52. It may be dangerous for a blind person to do something alone, but it is better than asking for help.
Agree _____ Disagree _____

53. Most sighted people are really interested in helping blind people.
Agree _____ Disagree _____

54. A person might as well accept the fact that blindness makes people pretty helpless.
Agree _____ Disagree _____

55. Many people become blind as a kind of punishment for something they did.
Agree _____ Disagree _____

56. There are things worse than being blind.
Agree _____ Disagree _____

57. One trouble that many blind people have is that their families don't understand them.
Agree _____ Disagree _____

58. Most people in the family act as though the blind person is a burden to them
Agree _____ Disagree _____

59. A blind person has to accept the fact that there are many things he simply cannot do.

Agree _____ Disagree _____

60. Even though it can create difficulties it is better for a person to live with his children when he gets older.

Agree _____ Disagree _____

61. Have you ever had contact with any social agency?

Yes _____ NO _____

If #61 WAS YES,FILL IN CHART.
What is the name of the agency? 61a. When did you go?
61b. How long did you go.?

NAME OF AGENCY	DATE OF INITIAL CONTACT	LENGTH OF CONTACT

62. Male _____ Female _____

63. White _____ Negro _____ Other _____

64. What is your religion?

Protestant _____ Jewish _____ Catholic _____ Other _____

INTERVIEWERS IMPRESSION:

WRITE A SUMMARY OF YOUR DIAGNOSTIC IMPRESSIONS. INCLUDE SUCH THINGS AS ATTITUDES OF THE INTERVIEWEE, MATERIAL NOT COVERED IN INTERVIEW SCHEDULE, YOUR FEELING ABOUT THE RELIABILITY AND VALIDITY OF THE MATERIAL, ETC. ETC.

APPENDIX II

GUIDE FOR INTERVIEWERS

General Instructions

Ask all the questions exactly as they appear on the interview schedule. Even if a question has been answered previously, ask it again exactly as it is on the interview schedule. If race and religion have been ascertained through observation, these questions do not need to be asked.

SPECIFIC INSTRUCTIONS ON CORRESPONDING QUESTIONS

1. Fill in the name prior to the interview and verify with interviewee.

2. Ask "how old are you?" "what is your age"? Compare interviewees answer with age recorded at State Commission and probe if there is a wide discrepancy. Check above appropriate box.

3. Self-explanatory

4. Self-explanatory

5. In asking the question, choose the category that applies to the interviewee, and write answer in space provided next to category.

6. Be specific as to actual location.

7. Omit if interviewee was born in U.S.

7. Omit if interviewee was born in U.S.

9. Self-explanatory

10. Omit if interviewee is foreign born

11. Check type of dwelling from observation. No question asked.

12. Self explanatory

15-18 If interviewee has children ask age and sex and ascertain employment status and whether or not they are living at home. This chart is to be filled in regardless of the place of residence of the interviewee if he has children.

19. Self explanatory

19a. Self explanatory

20. If schooling was obtained outside of the U.S. try to give equivagency in years and specify the answer given.

21. Probe for major source of income.

22. If employed, specify the occupation. Distinction between unemployed and retired is on the basis of age. Interviewees under 65 who are not working would be considered unemployed, while those not working and over 65 would be considered retired.

23. Omit if interviewee is unemployed or retired.

24. Self-explanatory

25. Probe and check appropriate answer.

26. Probe and check appropriate answers.

27. Probe and indicate frequency and facility on chart in terms listed on interview schedule.

28. Probe and summarize.

29. Probe, attempting to distinguish symptoms of cataracts from those of other conditions, such as nearsightedness or far-sightedness. Utilize chart provided.

30. Self explanatory.

31. If answer to this question is Opthamologist, proceed to question 32. If any other answer is given, turn to question 36.

32. Circle the order in which this opthmologist was consulted. Use the name of the doctor or the hospital that the interviewee has told you. Probe as to diagnosis, prognosis, and treatment and summarize.

32a. Probe and check appropriate response. If answer is yes, proceed to question 32b. If answer is no, turn to question 34.

32b. Probe and summarize

32c We are interested in finding out whether the doctor suggested the interviewee start treatment immediatdy, or could wait a specified period of time.

32d. Probe and summarize.

33. If this question is answered yes, procede to 33A. If the question is answered no, turn to 33F.

33A. Self-explanatory

33B Summarize and check appropriate response.

33C If this question is answered yes, procede to 33D. If the answer is no, turn to question 38 - p.8.

33D. Time span between leaving doctor and going to someone else.

33E. If answer to this question is opthamologist, repeat series of questions beginning with number 32. If any other answer is given, turn to question 36 p. 7.

33F. Summarize and check

33G. Use the name of the doctor the interviewee has told you.

33H. Time span between leaving Dr. and going to someone else.

33I. If answer to this question is opthamologist, repeat series of questions beginning with number 32. If any other answer is given, turn to question # 36. p. 7.

34. Summarize and check

34A. Probe and summarize

35. Use name of doctor interviewee has given you. If answer to this question is yes, procede to 35A. If the answer is no, turn to question 38 p. 8.

35A. Time span between leaving Doctor and going to someone else.

35B. If answer to this question is opthamologist, repeat series of questions beginning with number 32. If any other answer is given go to question 36.

Probe for diagnosis, prognosis, and treatment, then summarize

36A. Self-explanatory

36B. Probe and summarize

36C If the answer to this question is yes, procede to question 37. If the answer is No, go to question 38 p.8

37. If answer to this question is opthamologist, ask series of questions beginning with number 32. If any other answer is given, repeat series beginning with question 36.

38. We are interested in interviewees perception and understanding of the diagnosis. Probe and summarize

39. Self-explanatory

40. Use term 'cataracts' if interviewee uses the term in answering #38, or any other question.

41. We are concerned with relationship and not name and anticipate that interviewee will answer, a friend, sister, etc. That is all we want to know.

42. Probe and summarize in terms of favorable or unfavorable. Answer in same order as #41.

43. Probe for interviewees perception.

44. Same as #43

45. Self explanatory

46. Self explanatory

47. Self explanatory

48. Self explanatory

49-60 These are opinion questions in which we hope to get some indication about how well adjusted the interviewee is to his blindness. In asking the questions and in introducing them be sure to stress that we want to know **if they in general** agree or disagree with the statement. There can be no in between answers. Stress confidentiality and the fact that we are interested in their opinions about these statements. Don't get involved in long rationalization and explanation about the statements.

61. Define social agencies by giving examples such as The American Foundation for the Blind, Department of Welfare, Catholic Charities, C.S.S. If answer to this question is yes, fill in the chart. If the answer is no go to question #50.

62 Just check

63. Just check

64. This question is to be asked only when the answer has not been ascertained by observation.

Summary of Interview page 11

APPENDIX III

CODING INSTRUCTIONS

Box	Interview Question	
1	1	Number women 1 thru 500, men 501 up. No. to appear on interview guide and code card.
2	2	Code as follows: 1) 1-19, 2)20-29, 3)30-39, 4)40-49, 5) 50-59, 6)60-69, 7)70-79, 8) 80/
3	3,4,5	1) Married, 1A)married living with spouse, 2) widowed, 3)divorced, 4)separated, 5)single. Table for length of time. The time is to be transposed from current data 1) 1-5 years, 2) 6-10, 3)11-15, 4)16-20, 5)21-25, 6)26/.For example: 1A2 would mean 6-10 years ago and presently living with spouse.
4	6	1) United States, 1A) Rural, 1B)Urban, 1C)South, 1D)North, 2) Eastern Europe (Poland, Hungary, Russia), 3) Western Europe (Germany, England, France), 4) Southern Europe (Spain, Italy, Greece, 5) Puerto Rico, 6) America, 7) West Indies, (include Caribbean).
5	7	1) American Citizen, 2) other
6	8	1)born here, 2) under 5 years, 3) 5-10 years, 4)10-20 years, 5) 20-30 years, 6) over 30 years.
7	9	1) born here, 2) under five years, 3) 5-10 years, 4) 10-20 years, 5)20-30 years, 6) over 30 years.
8	10	Code using two parts, one for each parent X for male Y for female. Use the same code as in Interview Question (6) for the location of place of birth.
9	11	1)private home - but in actual no. of room (ex.1-6) 2) apartment " (ex.2-3) 3) Institution for the Blind 4) Nursing Home 5)Boarding Home 6)Old age Home 7)Rented or Hotel Room.
10	12	1)yes, 2)no. Note:Code dead child as no children.
11	13-18	1)for one child 2)for 2 children, etc. X for Male Y for female. I)living at home, II)not at home, A)Employed, B)not employed.Example 2X1A - 2 males employed, living at home 2YIIB - 2 females unemployed, not living at home.
12	19	1)own home, 2 children's 3) Relatives, 4)Friends.

Box	Interview Question	
13	19A	Code Age as it appears on Questionnaire, Sex: X Male, Y Female, Relationship 1)Boarder (non relative) 2) Relatives. Code A for employed, B for not employed.
14	20	Code circled number as it appears on Questionnaire.
15	21	INCLUDE ALL CATEGORIES THAT APPLY. Code as follows: 1)employment, 2)Self-Employment 3)DPW. AB 4)OASI, 5)Private Pension, 6)Children, 7)Relatives, 8)Insurance 9) Savings, 10)Spouse, 11) other.
16	22	1)Employed, 2) Unemployed, 3)Retired
17	23	1)Yes, 2) No
18	24	1) Never worked, 2) Industrial, 3)Clerical, 4)Supervisory, 5) Self-employed, 6)domestic
19	25	1)Alone, 2) Cane, 3)Dog, 4)Guide, 5)other
20	26	1) Work, 2)Recreation, 3)Services 4)Other
21	27	A) Work, B) Recreation.
22	27	C) Services, D)Visiting. Frequency. I)Daily, II) 1 or 2 times a week III) 1 or 2 times a month, IV) Rarely. Facilities 1) Walk, 2)bus, 3)Subway, 4)Taxi, 5) Private Car
23	28	Time Table dates from the present. 1) one year, 2)1-2 yrs., 3)3-4 yrs. 4)5-10 yrs, 5)10-15 yrs, 6)15-20/
24	29	A)Blurring of vision, B)Double Vision, C)Inability to see complete object, d) Black spot, E)Other, USE CODE OF QUESTION 28 NEXT TO EACH SYMPTOM FOR TIME. Example A3 / D2 /C1.
25	30	1)within first month, 2)within 3 months, 3)within 6 months, 4)within 1 year, 5)within 18 months, 6) within 2 years, 7)within 3 to 5 years, 8) after five years.
26	31	1)Opth. or occulist, or clinic. 2)Optometrist, 3) Family Physician, 4)Social orWelfare Agency 5) Friend, 6)other.
27	32	Code only the last Opth. seen. Code the number circled.
28	32A	Code 1) yes, 2)No

Box	Interview Question	
29	32B	1)Operation, 2)wait, then operate, 3)just wait, 4)nothing 5)untreatable.
30	32C	1)immediately, 2)within 6 months, 3)within 1 year, 4)wait 1-3 years, 5)wait indefinitely.
31	32D	CODE ATTITUDE OF FAMILY AS FOLLOWS: 1)Encouragement to follow instruction 2)neutral, 3)discouragement to follow Doctor's recommendation.
32	33	Code 1) yes, 2)no
33	33A	Code time as follows: 1)1-3 mos. 2)within 3-6 mons. 3)6 mos to 1 year, 4) 1 year to3 years, 5)3-6 years 6)7- 15+ years.
34	33B	1)for improvement 2) for no improvement 3)for worse than before.
35	33C	Code 1) yes, 2)no
36	33D	Code time table as follows: 1) 1-3 mos. 2)3-6 mos. 3) 6 mos - 1 year, 4)1-3 years, 5)3-6 years 6)7-15+
37	33E	Code 1)opth. occu. or clinic, 2)Fam Dr. 3)Soc. Welfare Agency, 4) friend, 5)other.
38	33F	Code this question in only one category. 1) Because of fear 2) Financial difficulty, 3)Didn't understand.
39	33G	Code 1)yes, 2) no.
40	33H	Code time table as follows: 1)1-3 mons. 2)3-6 mons, 3)6 mons to 1 year. 4)1-3 years, 5)3-6 years, 6) 7 - 15 years.
41	33I	1)opth. occu. or clinic 2)optometrist, 3)Family Dr. 4)Soc. or Welf.agency 5)friend, 6)other
42	34	1) too old, 2)med.complications other than eye condition. 3) med. complications pertaining to the eyes. 4)other
		THE FOLLOWING CODE BOXES REPLACE PAGE 6 PINK AND BLUE AND ALL OF THE PAGE(7) SERIES.
43	-	Code the actual number of contacts made with opth. excluding the last one
44	-	Code the time span between the first professional medical contact and last contact with an opth. 1)1-3 mons. 2) 3-6 mons. 3) 6 mons - 1 yr. 4)1-3 yrs. 5) 4-6 years. 6)7-15+ years.

Box	Interview Question	
45	-	Code the time span of onset of the illness (question 28) and the last contact with opth. using the above table.
46	-	If interviewees went to optometrist 1) yes, 2) no
47	-	Code the optometrists recommendation as follows: 1) need stronger glasses, 2)need for eye training 3) go see optha. clinic, etc. 4) Eyes are untreatable 5) other
48	-	If interviewee has been treated by more than 1 opth. code the actual no. of additional ones. Indicate by following: if they were referred for treatment A) yes, B) no.
49	-	Indicate if they went for treatment 1) yes, 2) no.
50	-	If treatment was surgery 1) yes, 2) no.
51	-	Was surgery successful 1) yes, 2) no.
52	-	Code if first contact was clinic 1) yes, 2) no.
53	-	Code if last contact was Clinic or private doctor. 1) Clinic 2) private doctor.
54	-	Leave this box empty
55	-	" " " "
56	-	" " " "
57	-	" " " "
58	38	Code as follows: 1)cataracts, 2) Have medical complications other than eye trouble. 3)glaucoma or other medical terminology, 4) don't know, 5)Other
59	39	1) Blue Cross, 2) Blue Shield 3)HIP 4)Private Med. Insurance 5) other, 6) No coverage.
60	40	Code 1) yes, 2) no
61	41	1) For Relative other than immediate family 2) friend, 3) member of immediate family 4) other.
62	42	Code number of successful operations numerically and no. of unsuccessful operations A)Successful B) Unsuccessful.
63	43	1) for $100, 2) $200, 3)$300, 4)$400-$600, 5)$600-$1000 6) don't know.
64	44	Code as follows: 1) 1 day to 1 week, 2) 8 days to 14 days, 3)14-30 days, 4)31 days - 3 months +.

Box	Interview Question	
65	45	Code 1) yes, 2) no
66	46	Code 1) Yes, 2) no
67	47	1) 1-3 mons. 2) 3-6, 3)6 mons to 1 yr. 4)1-3 yrs. 5) 3-6 yrs. 6)7-15 ≠ years.
68	48	Code 1) yes, 2) no.
69	49	10) disagreement, 20) agree
70	50	10) Disagreement 20) agree.
71	51	10) disagreement 20) agree.
72	52	10) disagreement 20) agree.
73	53	20(disagreement 10) agree.
74	54	10) disagreement 20) agree
75	55	10) disagreement 20) agree
76	56	20) disagreement 10) agree
77	57	10) disagreement 20) agree
78	58	10) disagreement 20) agree
79	59	20) disagreement 10) agree
80	60	10) disagreement 20) agree
81	-	This box is a score box - tabulate the total
82	61	A) Yes, B) No. INSTRUCTIONS: combinations are to be listed in the same box above each other. 1) welfare, 2)private family agency 3) agency for the blind, 4) hospital or clinic, 5)other Length of Contact: I)1-6 mons. II)7-12 mons. III) 1-3 yrs. IV) 4≠ years.
83	63	Code 1) White, 2) Negro, 3)other
84	64	1) Protestant, 2) Jewish, 3) Catholic 4) Other
85	-	Code Interviewers feeling about reliability of material 1) for valid, 2)invalid, 3)doubtful
86	-	Code prognosis that is on the original card. Code: 1) considered treatable 2) considered untreatable, 3) doubtful

USE WHITE CARDS FOR 1955 YELLOW CARDS FOR 1956.

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